

SPINAL COURIER

The spinal cord disability information source for Arkansans since 1989

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www.state.ar.us/ascc

New Case Manager in Fayetteville

Adela Martinez joined the Arkansas Spinal Cord Commission (ASCC) staff in September, replacing Benny Beals who retired this year after 25 years with the agency. She will be providing case management services to individuals with spinal cord disabilities in Benton, Carroll, Madison and Washington counties. In fact, Adela has already begun her quest to meet the individuals in the four-county area.

Adela obtained her BS in social work from the University of Arkansas. She is a licensed social worker and is bilingual, speaking fluent English and Spanish. Her ability to speak Spanish will be a definite asset to the agency and our His-

panic clients in Northwest Arkansas. Adela's past case management experience has included working with children and adolescents with disabilities.

Adela, husband Jason and two daughters, Natasha (age 3 1/2) and Vanessa (age 2), recently moved to the Fayetteville area from Fort Smith. Although she was born and raised in Panama, Adela is very familiar with Northwest Arkansas since her parents have lived in the West Fork area for quite some time.

Working full-time and raising two small children doesn't leave much free time. When she can Adela loves to spend time reading.



Adela Martinez is the ASCC Case Manager in the Fayetteville office.

The Commission members and staff of ASCC are fortunate to have such a qualified individual joining our agency. Please join us in welcoming Adela.

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AR Assistive Technology Alternative Financing Program

Through a U.S. Department of Education grant, Arkansas Rehabilitation Services, division of the Department of Workforce Education, established a \$1.6 million Alternative Financing Program to help Arkansans with disabilities purchase assistive technology to improve the quality of their lives.

The new loan program will have a tremendous impact on the lives of persons with disabilities as it provides a new means to purchase assistive technology that can help them live and work more independently. Consumers will be able to purchase all types of assistive technology devices and services, such

as wheelchairs, environmental control units, telecommunications devices, speech recognition devices, home office accessibility modifications and modified vans and lifts. These tools help individuals with disabilities to be more productive and participate more fully at home, school and work, as well as in the community.

Funding for technology has been a persistent barrier for individuals with disabilities. The new loan program will offer consumers increased options to finance purchases of assistive technology

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SPINAL COURIER

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Donations this quarter from:

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ASCC accepts tax deductible donations. The generosity of the many individuals and families, who over the years have made memorial

SPINAL COURIER Letters

Questions • Suggestions • Directions • Answers

Dear Editor:

I wanted to take this opportunity to caution my fellow Arkansans with spinal cord injuries about using the Baclofen pump for management of spasticity. Please know that, if you decide to use the pump and have one inserted, you are married to the

thing! No divorces!!! I have had severe spasms for many years—to the point they were cutting off my breath. I have had the baclofen pump for almost two years and it has been excellent in managing Continued on page 7 - see "Dear Editor"

From the Director

Some of you may remember from my last message that Ms. Frances Burnett wondered if she was the woman in Arkansas who had lived longest with a spinal cord injury with her 55 years. I couldn't imagine that she wasn't, but I was wrong! Thanks to our wonderful Arkansas Spinal Cord Disability Registry, we were able to find the answer. Three ladies have been in the "SCI Club" longer than Ms. Burnett! The longest living lady is Ms. Vena Hefner of Royal who was injured in 1945 while on active duty as a WAC in World War II. Ms. Burnett presently ranks #10 of longest living Arkansans with SCIs—the first is Mr. Bobby Williford of Benton, injured as a toddler in 1940. Now that's some longevity! We could learn a lot from Mr. Williford, Ms. Burnett and Ms. Hefner, as well as from Ann Works of White Hall who has 45 years in "the Club," according to her note. She spent 29 of those years as a speech pathologist in the Pine Bluff Schools, retiring this past year. Now that's some accomplishment! She thought she might be #2, but is actually #12 of the ladies and #28 overall. We have some hearty folks in our state!!!

Speaking of folks who have lived a long time and had an impact, I was saddened to learn of the death of Justin Dart, Jr. this past month. Justin, who lived with paraplegia for over 50 years after contracting polio as a teenager, was a dedicated advocate of human rights and particularly the rights of people with disabilities. He was known as the father of the Americans With Disabilities Act and sat next to President George Bush in 1990 when he signed it into law. He worked both sides of the issues, serving in many appointed disability service positions in the federal government, under three presidents, as well as as an activist who could be seen shouting on the Capitol steps when that tactic was needed. A Texan recognized by his big hat, Justin Dart visited Arkansas many times and provided us with leadership and an understanding of what was right about human rights. He was a great man and he will be missed but not forgotten.

Stay healthy and work on your longevity!

Cheryl L. Vines

donations, is greatly appreciated. Contributions are used to assist our clients through purchases of equipment and educational resources.

If you would like to make a contribution, please contact the Commis-

sion at **501-296-1788** / **800-459-1517** (voice) / **501-296-1794** (TDD), or send your donation to:

AR Spinal Cord Commission 1501 N. University, Suite 470 Little Rock, AR 72207

New Findings in Pressure Ulcer **Prevention and Treatment**

Pressure ulcers are a common, debilitating and costly complication of SCI, often requiring long periods of immobility, hospitalization and/ or surgery. Patients with SCI are therefore carefully instructed to perform regular, frequent pressure releases in order to maintain blood flow to the skin and avoid skin breakdown.

"Yet many individuals with SCI get pressure ulcers despite diligent pressure release behavior, and others get pressure ulcers that don't heal for years," said Jennifer James, MD, clinical assistant professor at the UW Department of Rehabilitation Medicine. James and her colleagues at the Seattle Veterans Affairs SCI Unit are finding that system-wide abnormalities, including deficiencies in the metabolic, anabolic and endocrine systems, are often present in patients with non-healing wounds. These complex medical conditions can both predispose a patient to pressure ulcers as well as prevent a wound from healing.

A pressure ulcer that has not healed after eight weeks of wound care and adequate nutrition is called a non-healing wound and may be an indication that the patient is in a catabolic state. Catabolism is a destructive metabolic process that converts living tissue to waste, in contrast to healthy anabolic metabolism, in which nutrients are converted to living tissue. "The catabolic state creates a vicious cycle of non-healing and multiple coexisting medical problems," James said, and "unless this systemic catabolic state is reversed, the wound cannot heal."

According to James, the most common and least recognized systemic abnormality evident in patients with non-healing wounds is

protein-caloric malnutrition (PCM), characterized by protein catabolism and loss of lean body mass (LBM). PCM inhibits the formation of collagen, which is the key protein in wound healing. Signs that PCM is present are low albumin and prealbumin, anemia, low serum zinc and reduced weight/height ratio.1 The severity of the pressure ulcer correlates closely with the degree of malnutrition, measured by albumin.2 Nonhealing wounds are also associated with low Vitamin B₁₂, a necessary factor in protein synthesis.

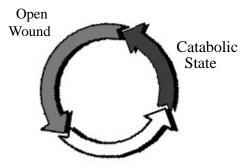
Nutrition supplementation with a high protein content is necessary but not sufficient to reverse the catabolic process. Low testosterone levels—a common deficiency in the SCI population³—can also hasten the loss of LBM4 and contribute to a catabolic, non-healing state. The medication oxandrolone, an agent that is structurally similar

Complex medical conditions can both predispose a patient to pressure ulcers and prevent a wound from healing.

to testosterone, can help correct this. "When used in conjunction with high protein intake, oxandrolone can stimulate or jump-start the patient out of the downward spiral of catabolism," James explained.

A loss of LBM and an increase in body fat are common in the SCI population and increase the risk for diabetes and heart disease. It is not unusual for a person with SCI to be both obese and very malnourished at the same time. LBM loss is also associated with impaired immune function and increased infections,

which further compromise the body's healing capabilities. Some medications that are frequently used by patients with SCI can cause malabsorption problems that contribute to malnutrition. Malnutrition can also result in decreased oxygenation to the skin, which undermines the healing of wounds and jeopardizes healthy tissue.



Multiple Coexisting **Medical Conditions**

"Once a pressure ulcer is present, the patient is already in a catabolic state," James said. But determining which came first—the pressure ulcer or the systemic decline—is a classic "chicken-or-egg" enigma. "We all wonder about that," she said. "Why do we have so many patients who do pressure releases regularly but still get pressure ulcers? And the reverse is also true" (patients who do not do pressure releases do not necessarily get pressure ulcers). Recent evidence collected and analyzed by James and other researchers at the Seattle VA now suggests that "patients who start out with decreased albumin and other metabolic deficiencies are predisposed to getting pressure ulcers because of their catabolic state, regardless of the pressure releases," James said.

Based on their findings, James and her colleagues have developed a new protocol for patients with pressure ulcers that includes testing for low albumin, B₁₂ and testosterone levels. Using this approach, they have been able to diagnose systemic abnormalities and treat non-healing pressure ulcers of

Continued on page 5 - see "New Findings"

SPINAL COURIER

Immunity and Spinal Cord Injury

By Tom Kiser, M.D., ASCC Medical Director

The body's ability to resist and fight off infection is dependent upon the immune system. Research is showing that persons with spinal cord injury (SCI) have a depressed immune system. The cause of this reduction is not entirely known, but there is evidence that it is probably due to many factors, one of which is autonomic dysfunction found in SCI.

Individuals with a SCI level above T_{10} (autonomic dysreflexia is present in individuals with a SCI level above T_{6-8}) were found to have alterations in

immune function, while those with a SCI at or below T₁₀ did not have decreased immune

function.¹ Both animal and human research studies have shown that repeated episodes of autonomic dysfunction (due to bladder distention or other painful stimulus) can result in a depressed immune function.

Another factor which can affect immune function is lack of exercise. Moderate exercise has been shown to improve the depressed Natural Killer cell function and T cell function (two important cell lines in the body needed to fight infection) in SCI patients involved in rehabilitation after being hospitalized.² Because of the nature of SCI, most individuals with a SCI live a sedentary lifestyle, and this contributes to a lower level of immunity. The addition of exercise to your normal daily routine may help fight infection.

Furthermore, certain drugs that are used in SCI are associated with a decline in immune function. Non-steroidal anti-inflammatory drugs (NSAIDs), diazepam (Valium®) and methylprednisolone all can depress immune response.

In addition, a diet high in fat consumption can decrease the effectiveness of Natural Killer cells and low protein intake can impair immune components in the body from macrophages to mature lymphocytes and can impair T cell response. About 50% of persons with SCI may also have noninsulin dependent diabetes, which is known to depress the immune function. A good well rounded diet, low in fat and with a good protein intake, can decrease the risk of diabetes and improve **immunity**. You can kill two birds with one stone, as the old saying goes.

Mark Nash, Ph.D. in a review article on this subject, makes the following recommendations to help increase your body's immunity to infection.³

- Get moderate exercise three to five days a week for a short time period. Extremes of just sitting around and excessive exercise are not desirable, as both can decrease the immune response.
- A diet containing sufficient protein and limited fat minimizes the adverse effect of poor diet on Natural Killer and T cells (this type of diet can also decrease your risk of diabetes).
- The by-products of alcohol and all recreational drugs, including tobacco products, suppress the immune system, so drink alcohol in moderation and avoid all tobacco products and recreational drugs.
- Stress management to prevent over-stimulation of your autonomic system is important. Adequate sleep, relaxation and counseling, if needed, can all be beneficial. Minimize the incidence of autonomic dysreflexia by good bowel and bladder management.

I would add two more recommendations that I feel are important to improving your immune



response to illness. Get a yearly influenza vaccination (flu shot) and a pneumococcal vaccination every five years. These two measures alone will help decrease your chance of illness during the influenza season and possibly a life threatening pneumonia.

References

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- 3. Nash, M. S. (2000, Summer). Known and plausible modulators of depressed immune functions following spinal cord injuries. *J of Spinal Cord Medicine*, 23 (2), 11-120.



Dr. Kiser has received a lot of calls about Therevac minienemas. The pharmaceutical manufacturer of the enemas has sold this medication to a sister company who has renamed the enema, Enemeez®.

So when you go to the pharmacy for a refill you may be told that the Therevac minienema is no longer available. Tell the pharamacist to look for it under the new name—Enemeez®. The new manufacturer is Western Research Laboratories and their phone number is 877-797-7997.

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First Ms. Wheelchair Arkansas Crowned

Carla Cates from Paragould became the first Ms. Wheelchair Arkansas Saturday, July 27, in Jonesboro.

She was chosen by a panel of six judges who evaluated the contestants in the areas of:

- personal accomplishments since the onset of disability (40%)
- communication skills (40%)
- self-perception/projection (20%)

Throughout the ceremony it was stressed that this is not a beauty contest. Instead, it is a competition to select the most accomplished and articulate spokesperson for women who use wheelchairs. According to the state pageant coordinator Ida B. Esh't, Carla will serve to promote a positive public image of disabled persons of all kinds. She will participate in the national Ms. Wheelchair America pageant next year.

Carla is employed at the Paragould Health and Fitness Center. She serves in a variety of capacities within her church and does guest speaking. In 1985 she was diagnosed with Fredreich's Ataxia that she said is related to muscular dystrophy. "Fredreich's affects

AR Assistive Technology Alternative Financing

Continued from page 1

and provide an alternative for those who do not qualify for traditional financing programs.

The program will begin accepting applications this fall. The loan program will be administered by Arkansas Rehabilitation Services, in partnership with the Arkansas Development Finance Authority (ADFA), the state financing agency. Call 501-683-**6053** for more information.

your coordination," Carla said, as reported in the Wednesday, July 30-31 edition of *Paragould Tri*bune. "When I was a kid I was really clumsy, but as time went on, it just got worse and worse."

She believes "people with disabilities have great potential given the opportunity. It is a person's attitude that makes all the difference in life." In her speech during the contest, Carla told the audience that true beauty comes from the inside. "How can we see the beauty in a person's heart? When they show love," The *Tribune*'s article reported that Carla said people could show that love by letting God show his own, by kindness, caring and courage. She went on to say, "And we show courage by overcoming what other people see as obstacles."

Other contestants included Monica Humble of Osceola, and ASCC

New Findings Continued from page 3

many years' duration that previously defied conventional inpatient and outpatient wound care.5 By identifying and reversing the catabolic state, "we're getting more patients to avoid surgery," James said. "We're beginning to think we should check testosterone and B₁₂ on routine annual checkups."

James insists that it's still important to do regular pressure releases. "But we need to look into other systemic factors that affect patients who get pressure ulcers. We're just discovering them. There is no data yet on the presence of systemic decline and the healing of wounds. This is a new frontier."

References

1. Allman, R. M., et al. (1995). Pressure ulcer risk factors among hospitalized patients with activity limitation. JAMA, 273, 865-870.



Paragould Tribune photo - GARY EXELBY

Carla Cates of Paragould, crowned Ms. Wheelchair Arkansas, answers questions from pageant M.C. Tyler Hawks while U.S. Army Pvt. Chad Calk looks on.

clients Jeanette Cline of Jonesboro, Michelle Grisham of Mountain Home and Rosie Jackson Sims of Pine Bluff. Rosie was chosen first runner-up.

Congratulations to Carla and to all the contestants!

- 2. Pinchcofshy-Devin, G. D., et al. (1986). Correlation of pressure sores and nutritional status. J Am Geriatr Soc, 34, 435-440.
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SPINAL COURIER

You Are a Valuable Member of Your Child's Team

by Deborah Swink, Special Education Supervisor, Clinton Schools

When children with disabilities enter the public school system, parents begin a process which consists of meetings, paperwork, evaluations and more paperwork! If the process is carried out well, the end result for children is a positive school experience with all the necessary supports in place. The best outcomes for children with disabilities are achieved when parents are willing and active members of their child's planning team.

The following are some tips for parents who want to become their child's best advocate:

- Believe in yourself and your abilities and remember that you have a right to be involved in all educational decisions concerning your child.
- Learn how to negotiate—don't let feelings of anger or denial stop the team process and the ultimate outcome for your child.

- Be prepared for the meetings. Prepare a list in advance if you need a reminder of the things you would like the team to cover. Try to bring any relevant information such as current medical reports, vision and hearing results or updated reports from counselors or therapists.
- Bring another family member or a trusted friend for "moral support."
- Be assertive, not aggressive. An assertive parent communicates his/her point of view clearly and positively, but also listens to what others have to say.
- When you don't understand something, ask for an explanation; sometimes the educational "jargon" needs to be defined or clarified.
- Share your dreams and your visions for your child. Talk about your child's strengths,

- interests and needs. Make suggestions about the kinds of support and services which you think will maximize your child's abilities.
- Understand your rights as a parent, even if you have to contact someone to assist you. The notices for meetings [usually] contain at least two sources for information should you need further help.

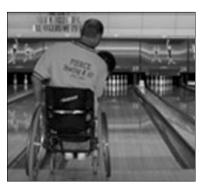
The most important thing to remember is that you are as important as the professionals you meet with to plan your child's educational program. Your input is an important and valuable contribution to the team planning process!

Reprinted with permission from News and Notes, January 2002, Arkansas Project for Children with Deafblindness, Arkansas Dept. of Education, Special Education, supported in whole or in part by the U.S. Dept. of Education, Office of Special Education Programs.

A League of His Own: Spotlight on Freddie Boozer

Freddie wheels up to the foul line in his rigid frame chair, locks his brakes, takes aim, swings his arm back then forward, releasing the ball—while holding his breath until the pins fly!

Bowling has been a part of Freddie Boozer's life since the age of seven and he radiates a natural enthusiasm for the sport. You want to go bowl a game after spending time with Freddie.



Freddie sets his sights on the pins.

He competes in a mainstream league, which recently began its 32-week season. Family members and friends make up the five-man team that Freddie has been on for eight seasons within this league. He bowls every week with an average of 189-191 per game.

Freddie is knocking on the door of competing nationally. His past bowling accomplishments include first place in a city tournament and second place in a state tournament.

It has only taken Freddie ten years to become an overnight bowling sensation! In the 70's he began bowling with his family. Later when his father's health temporarily forced him to the sidelines, Freddie took his place on a team during league play.

Freddie also played semipro baseball before his spinal cord injury,



Freddie Boozer, who has been bowling since the age of seven, does not allow SCI to keep him from the game.

which occurred in May of 1992. He readily admits, "It was difficult to get back into bowling after my injury. In 1994, I played basketball for the Rollin' Razorbacks. Gradually I got back into bowling, using a regular wheelchair and a 12-pound ball. My average at that time was 108 per game."

Freddie credits some key people in his rehabilitation process and, most of all, his family in helping him with his accomplishments.

Arkansas Rollin' Razorbacks 2002-2003 Basketball Schedule

October 12	Arkansas Valley Conference Tournament (AVC)	Home
November 2-3	New Orleans Invitational	New Orleans, LA
November 9	AVC Tournament	Muskogee, OK
December 7-8	Rollin' Razorback Invitational	Home
December 14	AVC Tournament	Fort Smith, AR
January 16-18	Pioneer Classic	Birmingham, AL
February 1-2	Dallas Texans Invitational	Dallas, TX
February 6-8	Bluegrass Invitational	Lexington, KY
February 22-23	AVC Championships	Norman, OK
March 7-9	Regional Tournament	TBA
March 27-29	National Wheelchair Basketball Tournament	Phoenix, AZ

All home games are played at Bill Harmon Recreation Center in Sherwood, AR. For more information, call 501-834-0987.

Dear Editor

Continued from page 2

my spasticity.

However, I was having trouble with refilling it due to deep placement and had scheduled an appointment for outpatient surgery to have my pump moved closer to the skin. As the pump was getting empty, I was going to have to turn it off, so I was told to change to baclofen pills and to titrate my oral baclofen up to 60 mg's—I went up to twice that (under my doctor's advice). Bad idea! When my pump was turned off, even with oral baclofen pills, the withdrawal caused me to have convulsions and rigors, and the only way to stop it was a chemically induced coma and ventilator.

Luckily, I was in the hospital because of pneumonia when this happened or I would likely have died! I ended up on a ventilator for five days and a baclofen catheter in my spine until I could have the surgery and get my pump refilled and turned back on! What I have learned since is it takes 100 times

more oral baclofen to have the effect of the interthecal baclofen!

I am now doing fine, but I had a very close call, just because someone thought I could do without interthecal baclofen for a few days. As it turned out, I couldn't tolerate being without it for just hours! I learned later that there have been other documented cases of reactions similar to mine and even a few deaths from stopping a pump cold turkey. Thank the Lord I made it back!

So, if you decide to go with a pump, be prepared to use it for life. Don't let it run dry, turn it off or think that you can alternate pills for the pump—you can't. Your life may depend on it!

Clifton Coates C₅ quadriplegia since 1976

Editors' note: If you would like to contact Cliff about his experience, call the ASCC Central Office and they will put him in touch with you.

New Resource for Hunters

Dream Catcher Outdoor Adventures, Inc. is an organization that plans to provide several hunting events for people with disabilities. They are in the process of building a wheelchair accessible lodge which should be completed by this upcoming hunting season.

For more information about this organization and planned hunts, contact Bobby Bower at:

Dream Catcher Outdoor Adventures, Inc.
720 East Fourth Street
Russellville, AR 72801
479-968-2370
toll free: 877-968-2370 or email:
dreamcatcher@cox.internet.com

Wheelchair Use and Injury Risk in Transportation Accidents

Seeking individuals who use wheelchairs as their primary means of mobility to participate in a research study conducted by researchers at the University of Pittsburgh!

This study is designed to investigate different aspects of transportation use and the risk and nature of injuries to wheelchair users involved in motor vehicle accidents.

Participants will be asked to answer a survey. This survey will take no longer than one hour to complete and will include questions about your wheelchair, use of transportation and any occurrence of motor vehicle accidents. Eligible subjects will receive \$20 for their time and effort.

If interested, please contact:

e-mail: tjs@pitt.edu

Dr. Thomas Songer 200 Lothrop Street, Suite B-400 Pittsburgh, PA 15213 **412-648-9296**

SPINAL COURIER — 7

Is Tai Chi for You?

by Shirley McCluer, M.D., Former ASCC Medical Director

Tai Chi is a form of slow, gentle exercise practiced for centuries in China with many reported health benefits. In recent years it has become increasingly popular in the U.S. (remember the Celebrex® commercial?).

Several research studies have been done to confirm many health benefits claimed by practitioners of Tai Chi, especially stress reduction and lower blood pressure. The August 5, 2002, issue of *Time* magazine touts Tai Chi as the perfect exercise, especially for seniors since it builds strength, agility and balance while moving at your own pace.

Although Tai Chi is normally done in a standing position, at least two individuals have produced video tapes showing variations that can be done while sitting. Both tapes are now in the ASCC Resource Center and available for checkout. Call the Resource Center at **501-296-1792** or **800-459-1517**. This is a brief review of both tapes:

- 1) *Tai Chi Anywhere* by Dr. Paul Lam, a family physician in Australia. This video is not specific for wheelchairs, but shows how the exercises are done normally, then how they can be adapted for sitting. You can decide which ones are possible for yourself. (83 min.)
- 2) Longevity Chair Qi Gong by Shifu Jiang Jian-ye, master Tai Chi and Kung Fu instructor and master Chinese calligrapher. The first 11-12 minutes of this tape are demonstrations of the instructor's various talents and have nothing to do with the topic—but can be interesting to watch if you are not familiar

with Tai Chi. All of the exercises are done in a sitting position. When you see how simple and easy the exercises are, you may think that they couldn't do much good, but don't dismiss them without a trial. (120 min.)

If any clients of the Spinal Cord Commission in the Little Rock area are interested in participating in a group Tai Chi exercise program, notify your ASCC Case Manager. If we can find an appropriate location and enough people are interested, I will be happy to help a group get started. I have been doing Tai Chi for nearly four years and I am firmly convinced of its benefits.

For more information about Tai Chi, call the ASCC central office at **501-296-1788** and the message will be referred to me.

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